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COPING EXPERIENCES WHEN CARING FOR A PERSON WITH SEVERE MENTAL ILLNESSES: A QUALITATIVE STUDY

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Within a community setting the responsibility of caring for a mentally ill individual, often falls on a family member. The aim of this study is to explore the coping experiences of carers of persons with severe mental illnesses. All patients were under the care of a team of community health care providers (Outreach team). Semi-structured interviews were conducted with seven family carers having relatives with severe mental illnesses (schizophrenia, depression and bipolar disorder). Participants' views on ways of coping were explored. Data collected was analysed using Interpretative Phenomenological Analysis (IPA).Three main themes emerged: 'Positively re-interpreting a situation', 'Seeking information and assistance' and 'Planning for the future'.Findings demonstrate that interventions should be sensitive to and responsive to the unique needs of carersand should target and respond to their need for knowledge, skills and support. Provision of support by health care providers in a community setting, were perceived as a necessary means of support and enabled carers to cope more effectively. Planning for the ill relative's future helped to re-assure carers that quality care would still be provided to the person, even when their own health and strength mightfail.

Keywords: Qualitative, Interpretative phenomenological analysis, Burden, coping experiences, Severe mental illness.

Introduction

Over the last century, the care of mentally ill persons has advanced in various aspects including pharmacological treatment and the in-patient psychiatric care setting, whilst at the same time has expanded beyond the hospital premises, by providing care and support within the community. This shift of care from hospital to community has caused family carers to become the most important care providers of their severely mentally ill relative (Rose, Mallinson&Gerson, 2006).

The National Alliance on Mental illness (n.d.), defined a severe mental illness as one in which the individuals have for the past year been diagnosed with a mental, behavioural or emotional disorder that influenced the person's level of functioning and required continuous treatment. Consequently, individuals with severe mental illness have a greater need for day to day care and supervision than individuals with other mental conditions (Chang &Horrocks, 2005).

The prevalence of mental health diseases in Malta ranges between 15 - 20% of the population (75, 000 people) and this is expected to increase drastically in the coming years (World Health Organization, 2001). This is expected to place an extra burden on family carers, especially considering the shift in care over the past years from long-term hospitalization towards care in the community. Additionally in such a scenario carers may feel incompetent to

provide holistic care and this could result in their experiencing considerable amounts of stress and burden (Chang &Horrocks, 2005; Samele& Manning, 2000). Being highly stressed and burdened not only leads to a detrimental effect on the carers' and ill relative's health, but could also influence the carer's decision to abandon care (Caqueo-Urizar, Gutierrez-Maldonado & Miranda-Castillo, 2009).

In the last couple of years, researchers have described coping as a factor which may influence outcomes such as carer adjustment and quality of life(Leventhal, Leventhal, E.A, &Contrada 1998). Coping is defined as cognitive, emotional or behavioural effort, used by the individual to deal with specific external and/or internal demands that surpass the person's habitual resources(Zeidner&Endler, 1996). Coping strategies can be divided into three categories which are: (i) Active Behavioural Coping Style e.g., seeking support and expressing feelings; (ii) Active Cognitive Style comprising acceptance, positive reassessment and finding strength in religious belief and (iii) Avoidance Style which is used when the individual ignores the problem and keeps worries to him/herself (Boschi et al., 2000). Family carerswho make use ofeffective coping strategies experience a decreased sense of burdenwhich contributed to the well-being of their own, their mentally ill relative, as well as that of other family members (Kartalova&Tedstone, 2010).

Furthermore the ill relatives of carers involved in this study were all being supported by a team of health professionals (Outreach Team) within a community setting. This support is given to persons with severe mental illnesses who are perceived as posing a greater risk for hospital admission,unless the necessary support is provided. Members of the Outreach team have direct links with all other aspects of community services, as well as with psychiatrists and other in patient mental health services.

In view of this, the aim of the present study is to explore and understand the way persons caring for an individual with a severe mental illness cope. Furthermore to the knowledge of the authors this is the first study that investigates the coping experiences of carers within a scenario where the patient-carer dyadreceived on-going support from community mental health care professionals.This information is of importance as it provides insight into the lived experiences of these individuals and also provides information regarding the fine tuning of possible support systems.

Methods

Participants

A qualitative, descriptive approach was used in this study, as it enables an in-depth exploration of the coping experiences of carers of persons with severe mental illness. The sample consisted of seven carers(four women and three men) of persons with severe mental illnesses. These carers were made up of parents, partners and siblings, with the most common role being that of the mother of the ill relative. Their mean age was 63 years, with ages ranging from 61-84 years, indicating that they were quite advanced in age. The mean long-term duration of care was 12 years.

A purposive sampling method was used and participants were recruited if they a) werefamily carers of persons with a severe mental illness, b) have provided support to ill relative for more than six months; b) were receiving on-going support from a community mental health team of professionals; c)were aged over 18 years and of any gender, d) were suffering of

schizophrenia, bipolar disorder ordepression either continuously or intermittently over a period of three years (in order to ensure that the patients were suffering of a **severe** mental illness.

Data Collection

Semi-structured interviews were used in this study and the interview schedule consisted of two sections.The decision to use semi-structured interviews was taken for two main reasons, as they allow sufficient flexibility in approach and that the same areas of data collection are covered with all participants(Bryman, 2008).The first section of the interview consisted of questions dealing with demographic aspects (e.g., age, gender) of the carer and person with severe mental illness. The second section consisted of seven open-ended questions, comprising questions delving into the coping strategies, the burden experienced by the carer and expectations about care services provided.Two practice interviews were conducted with two female participants. The interviews lasted on average 50 minutes and no difficulties were encountered by participants. The actual interview study was then conducted with 7 participants and lasted on average about 45 minutes.

Ethical Issues

The research study was carried out after approval was obtained from the University of Malta Research Ethics Committee. Potential participants were first approached by a Senior member of staff from the community mental health team (Outreach Team), and the aim and nature of the research study was explained. This procedure was adopted to ensure that potential participants did not experience any coercion to participate in the study Carers were provided with an information letter explaining the purpose of the study and their right to withdraw from this study at any point. Participation was voluntary and written consent was also obtained.Those carers who expressed their willingness to participate were then contacted by the first author (M.F).To ensure confidentiality of study participants,pseudonyms were applied throughout the study and all information collected was stored in a locked cabinet. A psychologist was also available should any participant experience distress during the interview.

Analysis

Interpretive phenomenological analysis (IPA) was used to analyse data from the interview transcripts. This stepwise approach as recommended by Smith et al. (2009) involved the following steps. Initially, the audio recorded interviews were transcribed verbatim and re-read to get a sense of the participant's experience. The second step involved reading and noting down significant points related to the carer's experience. These initial points were then used to document emergent themes. These themes were than compiled together and connections between them wereidentified to formulate clusters of themes. From these clusters super-ordinate themes emerged.

Results

Three major themes emerged. The first theme deals with 'Positively re-interpreting a situation',the second theme provides information on 'Seeking information and assistance' and

the final theme on 'Planning for the future'.These issues will be dealt with in further detail in the following section. Excerpts are also selected from the transcripts to illustrate the themeswhilst texts included within square brackets indicate author clarifications.

(i) Positively Re-interpreting a situation

Turning to religion and acceptance of the situation were the most cited coping strategies identified in this study by carers. Participants claimed that acceptance of their situation helped them to tolerate aspects which were unchangeable about theirill relative with mental illness.Daniela corroborated this point when she stated:

"So now I got used to it, it's like living for a patient. After all, he's my son. Nowadays, I am used to it"

It also enabled carers to decrease their tendency towards self-blame and helped them to reduce feelings of anger and distress, whilst providing further support to their loved one.

Moreover, carers obtained solace in their religious beliefs. Carers perceived that that they were not alone in having to support their relative who was mentally ill but that they were being supported also through their supernatural beliefs in God and the Virgin Mary. Consequently carers felt that there was a supernatural force that was actually protecting both themselves and the ill relative as described in the following excerpt by Rebecca:

"I don't complain…the Virgin Mary has always helped me together with all those who are in heaven. I feel that I am not doing too bad and I am not alone…"

Or as explained by Anne:

"To tell you the truth, even during the celebration of mass, you won't believe me… but after attending mass, I go inside as one person and I go out as another."

Othercarers identified personal traits that helped them cope with theircarer role, such as being an optimist or having a sense of humour:For instance as described by Daniela:

'I always take things lightly, that helps. I'm naturally cheerful and that does help me.'

Some participants kept themselves busy and continued to undertake activities that provided them with satisfaction, a feeling of accomplishment or even distraction, such as engaging in creative leisure.Rebecca exemplifies this in the following excerpt:

"…do you know what I do to ease my mind, I knit, either socks or a couple of blankets. Sometimes I knit, other times I play bingo. Sometimes I put things in order, or dust the furniture, I'm always doing something. That's the way I am."

(ii) Seeking Information and Assistance

Participants reported that in order to provide the best possible care, it was important to obtain more information about the disease and practical tips on how to deal effectively with the ill relative's difficult behaviour. Rachel described that such information had helped her feel more secure in her own ability to handle situations that might arise:

'I chose to learn more about the illness, so I increased my awareness, because I believe that if you don't understand, you feel frightened. So, I always seek to learn more about the illness and I even searched around to seewhere talks [dealing with mental illness] wereheld, and I attended courses as well, then once a month, we families used to meet up and share our experiences. Yes, I used to attend and I found them helpful.'

Additionally carer responses also demonstrated that the support received from health professionals in community services, were perceived as empowering for the participant, not only in regards to the patient's welfare but also for the mental health state of the carer him/herself. This is demonstrated by Chris' quote:

'But then at least I found help from the Outreach social worker and she helped me a lot. Honestly, for me she was, I am not sure how to explain this, but if it was not for her, I wouldn't

have known what do… or what would have happened to me...she realized what was happening to me…I was falling apart.'

Rachel also amplified on this point by stating:

"*The way I see it …is that the support we're given, empowers you … because when you are faced with a difficulty you're supported to deal with it…if there is no place to meet where you can discuss your difficulties or someone to whom you can turn to for help…you feel at a loss and you won't know where to turn to for help and so your problem remains …and the patient will get worse. However if you immediately contact the helpers [Outreach team] when you encounter any difficulty, you'll stop the problem from getting bigger …both for yourself [the carer] and the patient.*

Furthermore carers appreciated and expected that health professionals in the community team found the time to listen to their views, as clearly explained by Karl:

"I appreciate when they ask me, how are things at present? By asking me that they're sort of moving towards the source…because who can give details [about the ill relative] as much as I can , or any person who is living him?...Those are the persons who can say something…"

Other participants also cited support from family members as helping them cope with stress. In fact, mothers in this study claimed that their other children generally offered support both to themselves and their ill sibling as described by Daniela.

'My children help me a lot. They even call me to see how I am and if I am coping, they check if I am ok, even the neighbours … let alone my children. I have four children, and they all care for me... too much at times, especially my youngest son, sometimes he becomes rather annoying, but I never tell him.'

(iii)Planning for Future

With increasing age, carers have to tackle various challenges, dealing with their own health, while at the same facing challenges that may arise when caring for a person with a severe mental illness. For this reason they become increasingly concerned about the future care of their relative. To reduce some of this heavy mental burden, many carers had formulated care plans to ensure that their ill relative will be well cared for in future. Two parent participants stated that they would prefer other relatives to assume care if they were no longer fit to provide it, as exemplified by Steve:

'So you can imagine how much I'm concerned about him, I named my brother as heir in my will ..there is an agreement that when I die he will take care of him a bit since he [the person with mental illness] is an invalid.'

Another two carers (both parents) reported they had already arranged plans for their ill relative's future. Both these parents were advanced in years and feared that their failing health would not allow them to provide the necessary care required by their child. By making arrangements as described in the following excerpt the carers were ensuring continuation of care for their relative.

'I just can't wait until he's settled in a care home for the elderly, that will make me happy and healthy and it will make me feel fine.' (Daniela)

Discussion

This article has offered insight into the nature of coping strategies used by Maltese carers of relatives with severe mental illness. However this study contributes by exploring the coping experiences when the carers are being monitored and provided with support by a team of mental health professionals in the community (Outreach team).

Several studies have demonstrated that positively re-interpreting a situation promoteswell being (Yen et al., 2009; Zauszniewski, Bekhet&Suresky, 2010).Active cognitivestylesof coping such as turning to religion and acceptance were cited often by participants of persons with schizophrenia and depression.Participants religious beliefs helped participants give a meaning to their situation and provided solace both to themselves and to the ill relative. Acceptance helped them to start tolerating aspects which were unchangeable about the relative with mental illness.However all participants (i.e., those caring for persons with depression, bipolar disorder and schizophrenia) reported using behavioural coping strategies and engaging in physical and creative activities which provide them with satisfaction and distraction.An interesting finding in this study is that cognitive strategies were cited prevalently more amongst carers of patients with schizophrenia, whereas behavioural strategies were cited mainly by relatives of persons with bipolar disorder. A possible reason however for this observation is that thecarers of ill relatives with Bipolar disorder were men whoperceived the mental illness as a great burden since in addition to being the main breadwinner they were also expected to take *full* responsibility for additional chores(e.g., housework, care of the children) which previously fell under the responsibility of their partner.Additionally various studies (Nehra, Chakrabarti&Kulhara, 2005; Wancata et al., 2008) demonstrate that women are more likely to express their feelings and to seek social support and assistance from others. However, in order to identify specific coping strategies across gender, there is the need for additional research in this aspect.

In this study, similar to that found in other studies (Ohaeri, 2001), carers who had considerable amount of support from mental health professionals reported better coping strategies and perceived less stress than those who had less amounts of support.This correlates with Solmon's study (2000), which demonstrated that support and psycho-education groups ''improve adaptation and well-being, reduce stress and improve the outcome of the relative's problem'' (p.214). Other authors emphasized that psycho-education and support groups provide information on the disorder and the best intervention methods to be used, this would certainly reduce the uncertainty and confusion amongst carers. While improving the family environment, such interventions help to ease the burden felt while reducing the relapse rates (Wong, Lam, Chan & Chan, 2012). In spite of these advantages these interventions seem not to be widely used, it would be appropriate that such interventions should be offered to family carers as an integral part of the discharge planning.In fact this study has demonstrated that carers appreciated the role of continuous community support by a team of health professionals (Outreach team). As demonstrated in this research such support is a form of reference regarding local services available as well as empowering the carer with the necessary knowledge and skills to provide quality care. In this manner one could target the stress and burden thatcarers might be experiencing,as well as reducing unnecessary institutionalization of the patient.For instance in one study (Wancata et al., 2008) on parents of individuals with schizophrenia it was demonstrated that those carers who benefited from emotional support were more able to adapt to the situation and cope with the day to day problems they faced. Furthermore by providing support to the carers one might also be improving the relationships within the families. Rodriguez-Sanchez et al. (2011) suggested that family function is an important aspect that should be taken into consideration, as those carers that took important decisions together with their family, were those carers who felt in a better state of physical and psychological well-being.

All parents interviewed in this study were concerned about the future of their son or daughter that suffered from severe mental illness. This result is similar to that obtained by other resaerchers such as (Aschbrenner et al.,2011; Rose, Mallinson&Gerson, 2006).This study contributes however by demonstrating that some carerscope with their preoccupations regarding

the future care of their ill relative by formulating a care plan for their ill relative. Such care plans provide them with a sense of reassurancethat there will be someone available to continue providing care for the individual. In view of this, future care planning can be considered as another aspect that should be targeted by professionals providing support to carers. Such care planning includes information on residential and financial arrangements, as well as a means of practical and emotional support for individuals with mental health challenges (Chen, 2008).

Limitations

The small sample size used does not allow the results to be generalized. However generalizability was not a priority in this study, as it is not a requirement of qualitative research. Furthermore the sample was heterogeneous, encompassing carers having relatives with different types of severe mental illnesses. This was done as there was difficulty in finding participants willing to participate due to issues such as fear of stigma.

Conclusion

The results of this study provide details about the coping experiences of family care giversof relatives with a severe mental illness in Malta. As demonstrated in this study, community mental health professionals play an important role in carer empowerment and in helping carers enhance their coping skills, whilst supporting their existing skills and facilitating the development of new ones (Saad et al., 1995), thus improving the carer's quality of life. This is of importance in reducing carer burden and in a scenario where there is a move away from institutionalisation towards treatment and support within a community setting.

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